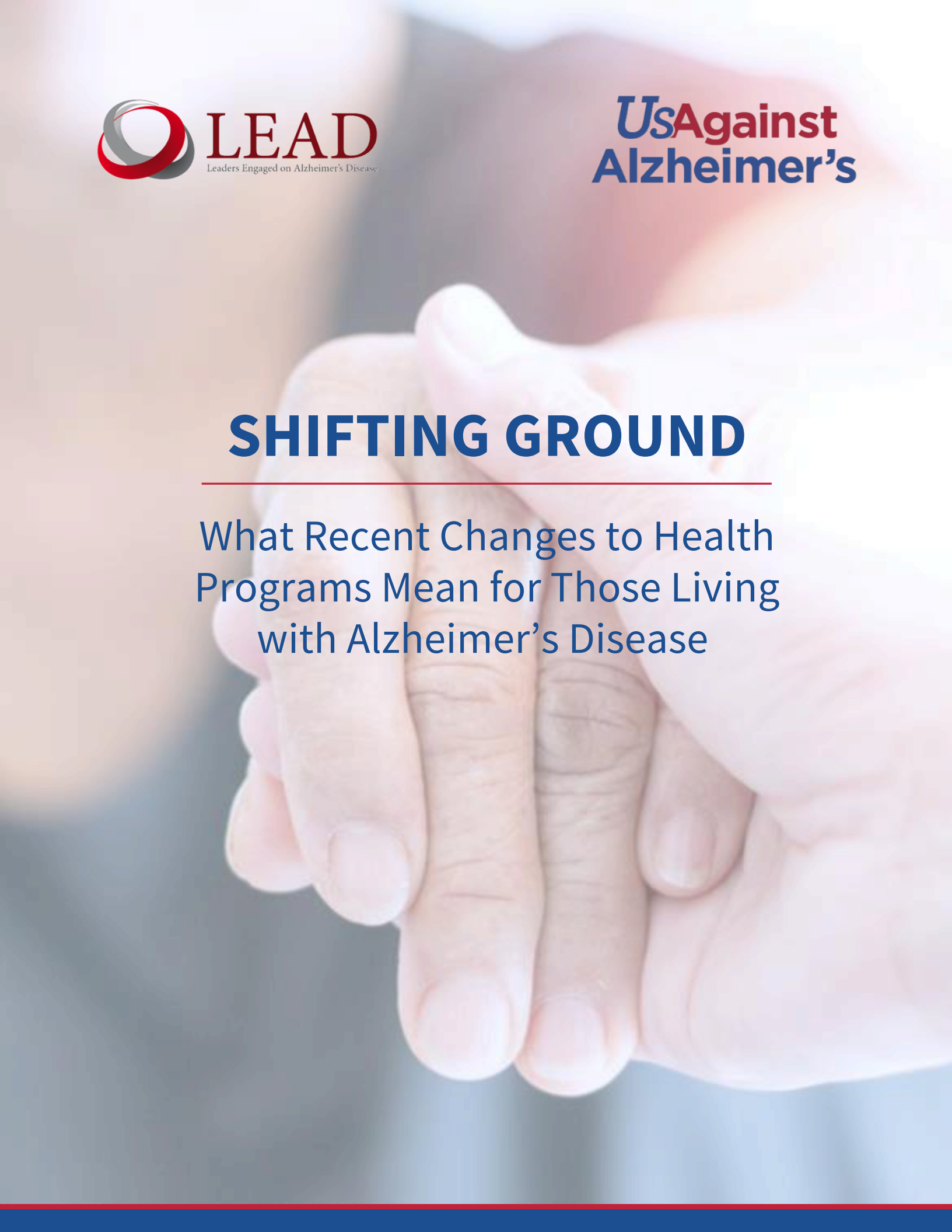
LEAD
Leaders Engaged on Alzheimer's Disease

UsAgainst Alzheimer's



SHIFTING GROUND

What Recent Changes to Health Programs Mean for Those Living with Alzheimer's Disease

The **Budget Reconciliation Act** of 2025 (Public Law or PL 119-21[1]) made significant changes to federal health and safety-net programs, including large reductions in Medicaid funding and changes to eligibility and program administration. Implementation of these changes at the federal and state levels are likely to have an outsized impact on many living with Alzheimer's disease or a related form of dementia (AD/ADRD), their care partners, and families.

Medicaid pays for most long-term services and supports (LTSS) such as home care supports in the United States, covering roughly half of all LTSS spending nationwide, and a substantially larger share in many **states**. Medicaid (NOT Medicare) also pays for most nursing home care in the U.S. Because Medicaid is jointly financed by the federal government and states, these changes are certain to shape state decisions about access to home- and community-based services (HCBS) and LTSS.

Although PL 119-21 does not explicitly reference AD/ADRD, the law's harmful effects on people living with these diseases are expected to be substantial. Nearly one in four adults with AD/ADRD living at home (non-institutional settings) rely on Medicaid for essential services over the course of a year. In addition, reductions in public coverage and reimbursement may have spillover effects on people who pay privately for care, particularly in rural and other underserved communities This is because providers with mixed public- and private-pay patient populations—such as hospitals, nursing homes, adult day programs, and home care agencies—scale back services or close locations in response to lost Medicaid revenue.

Keeping track of Medicaid coverage can be confusing. **Many states have state-specific names for their Medicaid programs**, such as Medi-Cal (California), Iowa Health Link (Iowa), MOHealthNet (Missouri), or TennCare (Tennessee) – and enrollees may be more familiar with their insurance company name such as Aetna or Blue Cross Blue Shield. All of this can lead to confusion and loss of coverage.

It is critical for states to consider the impact of these changes on people with AD/ADRD. Shortly after the passage of PL 119-21, a coalition of more than 40 patient advocacy organizations called the **Partnership to Protect Coverage** released **priorities for Medicaid** and encouraged state policymakers to adopt these priorities to mitigate some of the impact on access to Medicaid. For example, states can conduct proactive outreach and education about these policy changes and take steps to ensure smooth continuation of care for those who lose or transition coverage. States can also proactively screen individuals for exemption qualifications and develop user-friendly, accessible reporting systems to minimize red tape.

[1] PL-119-21 was originally known as the "One Big Beautiful Bill Act" or H.R. 1.

What This Means for You

This brief explains how federal policy changes are likely to affect care and access to services across Medicaid, Medicare, and the broader safety net – for individuals living with AD/ADRD and their care partners. It also provides a way for care partners and families of people living with AD/ADRD to be prepared and proactive in taking steps in anticipation of possible cuts to service and coverage.

- Cuts to long-term services and supports will impact people with AD/ADRD living at home.
- Individuals living with AD/ADRD and their care partners are at risk of losing vital coverage and services due to administrative changes to Medicaid, including new community engagement/work reporting requirements.
- Nursing home access and quality of care will be reduced for people living with AD/ADRD.
- People living with AD/ADRD who are eligible for both Medicaid and Medicare (so-called "dual-eligible" individuals) will be at increased risk due to financing changes that were made to the Medicare program as well.
- People under age 65 living with AD/ADRD are likely to face coverage gaps and barriers to early treatment.
- Uninsured individuals and those whose care is covered through safety-net programs are likely to face worsening AD/ADRD-related disparities.

Actions to Take Now

- Educate yourself about potential cuts and impacts in your state. Organizations such as Justice in Aging, National Association of Medicaid Directors, and the National Alliance for Care at Home, offer additional details on PL 119-21 impacts and resources for states, local governments, and individuals.
- Contact your state lawmakers to urge them to protect funding for home- and community-based services.
- Make sure your state Medicaid program has your most current address so you can ensure you are receiving all correspondence about any new reporting requirements that may be required of you as well as potential cuts to your services so you can appeal. Contact your state Medicaid program if you have any questions.
- Share your story about the importance of Medicaid coverage and home- and community-based services for your family.

The changes mandated by PL 119-21 are likely to have widespread impacts on the AD/ADRD community, and it is imperative that states mitigate how implementation will impact individuals and families living with AD/ADRD.

Cuts to long-term services and supports will impact people with AD/ADRD living at home

Impact: Families with Alzheimer's disease or other related forms of dementia (AD/ADRD) that rely on home-and community-based services (HCBS) to keep their loved one at home are likely to face increasing waiting lists at home care agencies. States' coverage under Medicaid for HCBS is an optional benefit under federal law, which means it is more likely to be cut by states as they struggle with balancing their budgets in response to the federal Medicaid policy changes aimed at reducing the federal government's share of program costs. As of May 25, 2026, Colorado, Idaho, Iowa, Missouri, Nebraska, and North Carolina are among the states that have announced cuts or elimination of HCBS. Such cuts raise grave concerns about increasing burdens on already strained care partners and challenges for families who wish to keep their loved ones with AD/ADRD at home but may need to instead move them into long-term care facilities.

- Approximately 5.1 million Medicaid enrollees receive HCBS, with about half accessing care through state waiver programs that allow services to be delivered at home rather than in nursing facilities. These services are especially critical for the one in four people with AD/ADRD living at home who rely on Medicaid over the course of a year. Medicaid's essential role typically grows as cognitive impairment advances and paid care becomes necessary. These administrative changes may limit families' ability to keep loved ones with AD/ADRD at home by complicating access to HCBS, unintentionally reinforcing reliance on nursing facilities and undermining long-standing federal and state goals to support aging in place.

- In response to the federal Medicaid cuts, states are likely to reduce access to home care by limiting HCBS waiver enrollment, further increasing already long waiting and interest lists that exceeded 600,000 people in 2025. In 2025, people waited an average of 32 months to receive HCBS services—37 months on average for people with intellectual or developmental disabilities (I/DD)—and nearly 48 months in states that do not screen for eligibility. During these extended waits, many people lack access to specialized AD/ADRD supports such as adult day services or sufficient personal care hours. This increases caregiver strain and the risk that individuals will be forced to move into long-term care facilities. Federal Medicaid cuts threaten to worsen dramatically both HCBS wait times and the number of people with AD/ADRD forced to leave their homes and be pushed into long-term care facilities.

- People with I/DD comprise nearly 74% of those on HCBS waiver waiting lists, and this group includes a growing number of adults aging into AD/ADRD. Among approximately 180,000 adults with I/DD over age 60, an estimated 11,000 are already living with AD/ADRD, with risk increasing sharply with age. Individuals with Down syndrome face particularly high risk: estimates suggest 50–90% develop Alzheimer's disease after age 60.

- Extended HCBS waiting periods delay access to essential supports for people with co-occurring I/DD and AD/ADRD. This increases reliance on family care partners and with it, the likelihood that individuals will be unable to remain at home. New reductions in federal Medicaid funding are likely to further limit waiver enrollment, worsening delays for a group of people with rapidly escalating care needs and few alternatives to Medicaid-funded services.

Individuals living with AD/ADRD and their care partners are at risk for losing vital coverage and services due to administrative changes to Medicaid, including community engagement/work-reporting requirements

Impact: Family care partners of people living with Alzheimer's disease or a related form of dementia (AD/ADRD) are likely to face increased administrative burdens, greater risk of coverage disruptions, and added stress as they navigate more complex Medicaid eligibility and reporting requirements—for both their loved ones and themselves.

- According to AARP, approximately 4.3 million family care partners rely on Medicaid for their own healthcare coverage, heightening the risk that coverage disruptions will directly affect care partners' own health and ability to provide care.

- New community engagement (work) reporting requirements will begin in 2027. As outlined in an interim final rule (IFR) released by the Centers for Medicare and Medicaid Services (CMS) on June 2, 2026, it will be more difficult to demonstrate medical frailty, which is one of the exemptions for community engagement/work reporting requirements included in PL 119-21. Under the IFR, individuals — even those with serious medical conditions such as AD/ADRD — must demonstrate they cannot work. Ironically, such administrative changes will increase red tape, making Medicaid more bureaucratic and less efficient.

- AD/ADRD care partners are also vulnerable to these changes: In the June 2 IFR, CMS proposed to exempt individuals whose primary responsibility is taking care of a family member with a disability as defined by the Americans with Disabilities Act (ADA), but care partners will still need to meet the administrative reporting requirements in order to both receive and keep their own coverage through Medicaid.

- It was also expected by some that self-attestation by Medicaid recipients or caregivers would be permitted; however, in the IFR, Medicaid gave states the option to allow it in 2027, but it will not be permitted by CMS in any state starting in 2028. This is likely to lead to further coverage losses.

- Even before the IFR was released and changed some of the assumptions many states had made for implementation, some had raised concerns already: On May 29, 2026, six governors **sent a letter** to Health and Human Services Secretary Robert F. Kennedy, Jr., outlining their concerns with the implementation of the law.

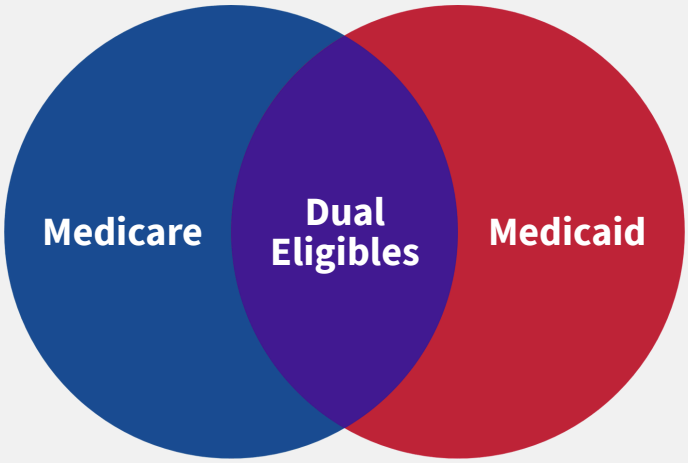
Nursing home access and quality of care will likely be reduced for people living with AD/ADRD

Impact: People living with Alzheimer's disease or other related forms of dementia (AD/ADRD) who require nursing home care are likely to face reduced access and declining quality.

- Medicaid is the primary payer for nursing home residents, including roughly 600,000 residents who live with AD/ADRD.
- Medicaid nursing home payments already average approximately 82% of nursing home providers' actual costs. Further Medicaid payment reductions may force facilities to reduce staffing, limit admissions, or close altogether, particularly in rural and underserved areas.
- The December 2025 repeal of minimum federal staffing requirements removes a key care quality safeguard, making it unlikely that nursing home quality will remain stable as financial pressures intensify due to Medicaid cuts.

While not a direct provision of PL 119-21, in December 2025, the Centers for Medicare and Medicaid Services repealed the federal minimum staffing standards for nursing homes, which removes an important quality safeguard at the same time Medicaid payment pressures are intensifying. This change occurred after a provision in PL 119-21 delayed the enforcement of new Medicare/Medicaid nursing home staffing rules until September 30, 2034. Together, these changes may increase risks to access and quality of care for nursing home residents—more than half of whom live with AD/ADRD.

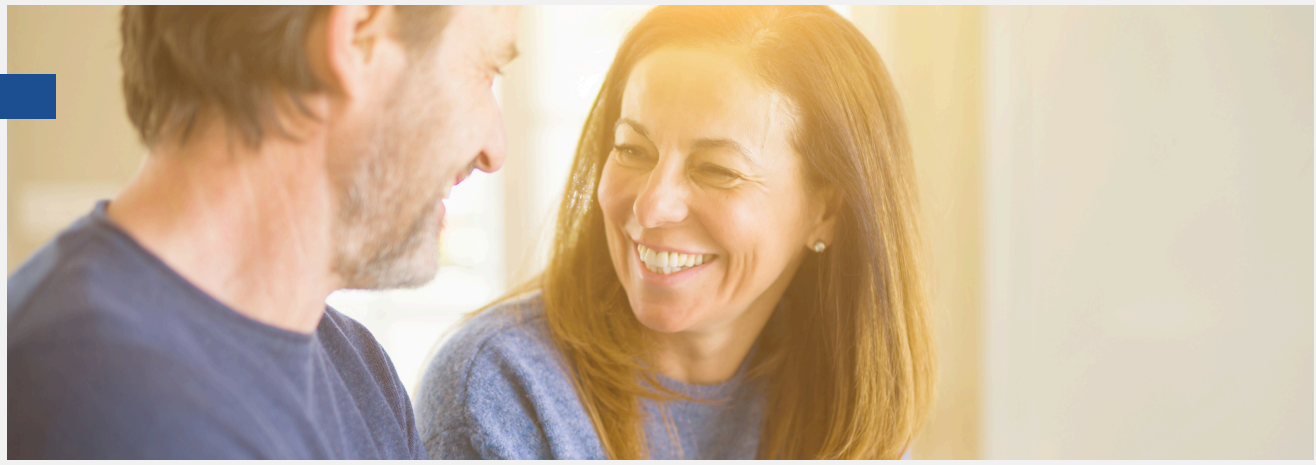
Dual-eligible individuals living with AD/ADRD will be at increased risk due to financing changes that were made to the Medicare program as well



Impact: Automatic Medicare payment cuts and benefit changes required by PL 119-21 are likely to strain access to care for people living with Alzheimer's disease or other related forms of dementia (AD/ADRD), particularly those who are eligible for both Medicare and Medicaid (dual eligibles).

- Nearly all people with AD/ADRD are enrolled as Medicare beneficiaries.
- Automatic Medicare cuts (Pay-As-You-Go): According to the Congressional Budget Office, PL 119-21 increases the federal deficit by at least $3 trillion, which will trigger automatic Medicare cuts of approximately 4% annually. This amounts to hundreds of billions of dollars in Medicare cuts over the next decade. While Congress has typically delayed or waived these cuts, there is no guarantee given current political constraints that this pattern will continue.
- Reduced Medicare payments may lead Medicare Advantage plans to leave markets, scale back supplemental benefits, increase premiums or cost-sharing, and/or narrow provider networks—affecting access to care for people with AD/ADRD who rely on coordinated services.
- Payment reductions and budget uncertainty could jeopardize promising demonstration programs and care models focused on AD/ADRD care coordination, such as the Centers for Medicare and Medicaid Services (CMS) **GUIDE Model**.

People under age 65 living with AD/ADRD are likely to face coverage gaps and barriers to early treatment



Impact: Between 175,000-200,000 people in the US under age 65 are living with Alzheimer's disease or a related form of dementia (AD/ADRD). Under current law, even after qualifying for Social Security disability benefits, these individuals face a statutory 29-month waiting period before becoming eligible for Medicare coverage. A small number (25% or less) may become Medicaid beneficiaries as they wait.

- New Medicaid reporting requirements are likely to limit the ability for persons with young onset AD/ADRD to get coverage and receive AD treatment drugs in the early stages of the disease in which they are most effective in slowing disease progression.

Uninsured and individuals whose care is covered through safety-net programs are likely to face worsening AD/ADRD-related disparities

- Between 6% and 10% of adults above the age of 65 do not have Medicare and must rely on Medicaid and safety-net providers for basic healthcare.

One in four rural adults have basic health coverage or long-term services and supports through Medicaid

- Although PL 119-21 establishes a $50 billion fund for Rural Health Transformation Grants, these funds are limited in scope and timing and are different in each state. That means any beneficial impact of these resources on care in the next five years are unclear and unlikely to replace sustained Medicaid funding that rural providers depend on for AD/ADRD care and long-term services.

- Medicaid cuts threaten more financial instability for already struggling rural hospitals and nursing homes.

- Service reductions, and potential facility closures, will force patients to travel farther for care or go without it altogether.

American Indian and Alaska Native people utilize Medicaid at higher rates.

- Tribal citizens face the highest risk factors for AD/ADRD of any group of people in the U.S. AD/ADRD is only recently being recognized in these communities as a significant public health issue.

- State cuts to Medicaid funding and loss of coverage through burdensome reporting requirements will disproportionately impact these communities, where geographic isolation and underfunded Indian Health Service healthcare facilities already present significant barriers to health and wellbeing.

Other Limits on Health Spending Today Could Have Future Impacts On AD/ADRD

Research is increasingly pointing to the importance of risk reduction in delaying or mitigating AD/ADRD. Efforts to reduce health investments may have unintended consequences on people at elevated risk of Alzheimer's disease or other related forms of dementia (AD/ADRD), people with mild cognitive impairment, or early-stage AD/ADRD.

- *Reductions in nutrition assistance and access to primary care may worsen food insecurity and increase chronic health conditions such as hypertension, tobacco use, type II diabetes, and depression, increasing long-term risk factors associated with cognitive decline and AD/ADRD.*

- *Pressure on Medicare spending could limit access to emerging diagnostics and treatments, as we have seen with Alzheimer's disease PET scans. Access to biomarker testing, advanced imaging, and treatment options may be limited, delayed, or denied.*

- *Other dramatic reductions in chronic disease staff and funding at the Centers for Disease Control and Prevention's Center for Chronic Disease and Health Promotion will impact state and national public health efforts to promote brain health and AD/ADRD risk reduction.*